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ORIGINAL RESEARCH

Challenges and coping strategies of parents of children with autism on the Kenyan coast

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ABSTRACT

Introduction: Research on the challenges of raising a child with autism is mostly conducted in Europe, North America and Australia, and has revealed that parents have to come to terms with living with a lifelong developmental disability. In addition, parents are faced with numerous concerns, such as caring burdens, poor prognosis, and negative public attitudes. Virtually no research has been conducted in Africa on this subject.

Methods: Thirty-seven interviews and eight focus group discussions were conducted with parents of children with autism and professionals in regular contact with these parents from rural and urban counties of the Kenyan coast. The study investigated challenges faced by parents and how they cope with those challenges. A purposive–convenience sampling procedure was used in selecting the study participants. A digital recorder was used to record all the interviews and focus group discussions. Transcriptions were done in Swahili, translated into English, and then imported to the NVivo software program for content analysis.

Results: The results indicate that parents of children with autism on the Kenyan coast experience common challenges including stigma, lack of appropriate treatment, financial and caring burdens regardless of their religious and cultural backgrounds. Coping strategies applied by parents comprised problem-focused aspects that involve diet management and respite care, and emotion-focused aspects that consist of beliefs in supernatural powers, prayers and spiritual healing.

Conclusions: This qualitative study reveals a range of challenges that could have significant impact when caring for a child with autism. Coping strategies applied by parents target the physical health of the child and the psychological wellbeing of the parent.



Consideration of these outcomes is vital as they could impact the initiation of a community-based rehabilitation service delivery in rural settings where parents play an active role.

Key words: Africa, autism, children, focus groups, interviews.

Introduction

Research on the challenges of raising a child with autism is mostly reported from Europe, North America and Australia¹ and has revealed that parents have to come to terms with living with a child who has a lifelong developmental disability. In addition, parents are faced with numerous concerns, such as caring burdens, poor prognosis, and negative public attitudes^{2,3}. Other challenges include increased financial burdens, misconception of the nature of autism and low levels of social support^{4,5}. Availability of services for treatment is limited, even when a proper diagnosis is done⁶.

Although awareness about autism has increased in resource-rich countries, autism still remains poorly understood by most Kenyans and other people in sub-Saharan Africa⁷⁻⁹. A recent study conducted on the Kenyan coast revealed that there is a mixture of perceptions by the local people on the causes of autism¹⁰. Both preternatural and biological factors were thought to cause autism. These views could influence the challenges and coping strategies of parents with children with autism in this region.

Autism is a misunderstood condition in Kenya, and in Africa in general. Lack of awareness limits access to appropriate services that may improve quality of life and prognosis in children affected by autism. In addition, parents of children with autism face challenges such as single parenting or divorce, childcare needs and lack of financial resources, all of which have negative effects¹¹. Information on how these parents cope with these challenges is scant.

The stress of living with a child with autism can affect the psychological and emotional wellbeing of parents and generate conflict between them^{12,13}. This aspect is worsened by the poor prognosis of autism¹⁴. Parents of children with autism experience increased personal stress, problems in interpersonal relationships and increased isolation^{15,16}. Parenting stress has a negative impact on the mental and physical health of parents of children with autism^{17,18}. Factors that contribute to elevated stress in parents of children with autism include the child's behavioral problems, lack of adequate professional support, and social attitudes towards individuals with autism. A study conducted by Werner¹⁹ revealed that lives of persons in families that have children with autism often revolve around dealing with the child's unusual behaviors. These behaviors may adversely impact on family function.

Stigma is one of the most difficult aspects of public encounters experienced by parents of children with a disability²⁰. Stigma is a social construct defined as a mark of shame or discredit, characterized by guilt or disgrace²¹. Components of stigma include labeling, stereotyping, separation, status loss, and discrimination²². Parents of children with autism often experience stereotyping and negative public reactions. These parents need adaptive strategies to cope with the problems manifested in public encounters.

Studies in resource-rich settings have revealed that parents harness a range of strategies to cope with these challenges. Gray²³ highlighted three strategies used by parents of children with autism: accommodation of the biological basis of autism, in which the parents accept that the disorder is a result of natural causes; resistance to the biological basis of autism, where parents tend to view autism as a



consequence of external influences or forces; and the use of spiritual beliefs to understand their situation, which is based on beliefs in God and the conviction that everything is possible through faith. Other coping strategies include accessing information, withdrawal from social interactions, shifting expectations, and working towards inclusion and greater acceptance of the child^{24,25}. Because Africa has a wide range of sociocultural environments, conceptions of autism are relatively diverse²⁴ and might influence coping mechanisms of parents of children with autism in different ways.

Folkma and Lazarus developed and revised a measure of coping²⁶. The measure is made up of a series of predicates, each portraying an action in which people engage when stressed. Problem-focused coping aims to alter the source of the stress, while emotion-focused coping tries to reduce or manage the emotional distress associated with the situation²⁷. Problem-focused coping tends to predominate when people feel that something can be done, whereas emotion-focused predominates when people feel that the stressor must be endured²⁷. Because conceptions of autism in Africa are diverse compared to other continents²⁸, coping mechanisms of parents of children with autism may be different.

Although coping with autism has been examined in a number of studies from resource-rich settings, there is a paucity of research that has been conducted with parents of children with autism in Africa. Unpublished work provides scant information on how children with autism are perceived^{8,29}. Lack of evidence-based information on challenges and possible coping strategies of parents of children with autism could negatively influence initiation of community-based rehabilitation. Community-based rehabilitation is a strategy initiated by WHO for rehabilitation, equalization of opportunities, poverty reduction, and social integration of persons with disabilities and their families³⁰.

Building on this scanty evidence base and results of a disability study conducted in Kilifi County³¹, which revealed that a child with a disability influences the expectations of caregivers, the present study set out to explore the life

challenges of raising a child with autism on the Kenyan coast, and how parents respond to them.

Methods

This study utilized a qualitative design and applied a phenomenological methodology. This methodology was thought appropriate as the study examined real-life experiences brought about by the existence of a child with autism in the family. The study addressed two research questions:

1. What are the challenges faced by parents of children with autism on the Kenyan coast?
2. What coping strategies do these parents apply?

Study site

The study was conducted in two counties of the Kenyan coastal region: Kilifi and Mombasa. Kilifi County is rural with a poverty level of 71% and a literacy level of 55%, while Mombasa County is urban with a poverty level of 38% and a literacy level of 86%. The monthly incomes are US\$8 and US\$33 for the rural- and urban-dwellers respectively³². The predominant inhabitants from the two counties are from the nine Mijikenda subgroups, the Swahili, and the Arabs. These inhabitants have different cultural beliefs and practices. The Kenyan coast was seen as a good area for this study due to its diversity in both culture and traditional practices.

Study participants

Two groups of participants were recruited: parents of children identified with autism and professionals in regular contact with parents of children who have autism. A total of 103 participants were recruited: 60 from the rural county and 43 from the urban county. Participants were from different cultural backgrounds and religious beliefs, including Christians, Muslims, and traditionalists. Kilifi County mostly follows the Mijikenda traditional practices, although there are some influences of the Swahili and Arab cultures and



traditions. Mombasa County follows mainly the Swahili and Arab traditions and practices. Elements of Mijikenda culture are seen in some parts of the county. Thirty-seven participants from both counties participated in in-depth interviews of 30 minutes each, while 66 participants took part in focus group discussions (FGD), lasting for an hour. Participants from the two counties did not know each other. The participants who took part in the in-depth interviews were different from those in the FGD (Table 1).

Sampling procedures

A purposive–convenience sampling procedure was used to recruit the study participants. This sampling method was deemed appropriate for this study as it sampled participants thought to have the time and ability to give the required information. Parents of children with autism from the rural county were recruited through the neuro-assessment clinic at Kilifi County Hospital while those from the urban county were selected through an educational assessment and resource center. The neuro-assessment clinic comprises of a neurologist and two pediatric clinicians, while the resource center team is multidisciplinary, made up of assessment teachers, hospital rehabilitators (physiotherapist, occupational therapist, and orthopedic technician), a pediatrician, an ear–nose–throat specialist and a social worker. An evaluation report from the team is necessary before a child is put into a special education program.

Special needs teachers were recruited from specialized units and schools, while clinical officers were from the county hospitals. Social workers were selected from the Ministry of Culture and Social Services.

Data collection methods

In-depth interviews and FGDs were utilized in the data collection. The interviews and focus groups were facilitated by the first and third authors (JKG and KR). As the study aimed at obtaining the emic perspective and a broad range of views of participants on the issues under investigation, these two methods were deemed appropriate for this study. Thirty-seven interviews were

conducted (19 in Kilifi County, 18 in Mombasa County), and eight FGDs were carried out, four in each county. The interviews and focus groups were facilitated by the first author (JKG). The interviews and FGDs were guided by questions that were set for parents and professionals. The guiding questions were formulated by the researchers based on the research questions to be answered (Table 2).

Data storage, analysis, and interpretation

The interviews and the FGDs were recorded, transcribed, and translated into English from Swahili, and imported to the NVivo v7 software program (QSR International; <http://www.qsrinternational.com>) for storage and management. Content analysis as described by Taylor-Powell and Renner³³ was utilized to analyze the data. The first author (JKG) read the text three times for familiarization to identify key issues. The data were then coded using free nodes to identify consistencies and differences. All the free nodes with similar messages were grouped into tree nodes, each bearing a name of a theme. Connections within and between themes were identified for interpretation. Another author (AA) read the transcripts for triangulation. Conflicting ideas were jointly discussed and analysis was utilized to clarify interpretations for consensus.

Ethics approval

Written informed consents were attained from the participants. It was emphasized that participation in the study was voluntary and there were no subsequent consequences for refusal or withdrawal. The study was approved by the Kenya Medical Research Institute National Ethics and Review Committee (SSC #2270).

Results

The results section of this study describes the challenges for parents of children with autism on the Kenyan coast regardless of cultural or religious affiliations. Integrated within these challenges were coping strategies parents in which engage during the parenting process. These results are divided into two broad themes: caring challenges and adapted coping strategies.



Table 1: Demographics of study participants from rural Kilifi County (n=60) and urban Mombasa County (n=43)

Group	Age range (years)	Educational level	Religious affiliation	Rural – Kilifi County	Urban –Mombasa County
Parents of children with autism	25–75	No formal education at tertiary institution	Christianity; Islam; traditional	30	21
Special needs teachers	30–52	Diploma – degree	Christianity; Islam	16	12
Clinical officers	35–48	Diploma – degree	Christianity; Islam	12	8
Social workers	35–50	Diploma	Christianity	2	2

Table 2: Guiding questions for parents and professionals for interviews and focus groups

Guiding questions for parents	Guiding questions for professionals
<ul style="list-style-type: none"> • What challenges do you encounter in your day-to-day caring of your child with autism? • How do you cope with these challenges? • What kind of assistance or support do you get? • Do you have anything more to add? 	<ul style="list-style-type: none"> • What challenges are faced by parents of children with autism in this area? • How have these challenges affected them in relation to their parenting duties? • What coping strategies do these parents apply as they care for their child with autism? • How have these strategies helped them? • Do you have anything more to add?

Caring challenges

This theme has four subthemes: stigma, lack of adequate health services, financial burden, and care-giving burden.

Stigma: Most parents and the professionals from rural and urban settings interviewed viewed parents of children with autism as being stigmatized and sometimes blamed for their child's condition and behavior.

People end up blaming me saying that I am raising my child in a bad way. I'm seen as an irresponsible mother. I feel ashamed of myself. (Interview, parent, rural county)

They are suffering because as Africans, in any society, you know your hope is to get a normal child. These parents are disregarded. (Interview, teacher, rural county)

There are those people like in a church. When they see a child moving up and down and disturbing people, they blame the parent. Then you are banned from church services. (FGD, parent, urban county)

Most participants from the two counties highlighted non-acceptance of the child with autism by peers, family members, relatives, and the wider community. Lack of acceptance was expressed in the form of social exclusion of the child.

I would like the family, relatives, neighbors and the community to accept my child because no one is happy to have a child with this condition. (FGD, parent, rural county)

There is a child at my aunt's place, he is dirty, eats alone, and when he comes close to other children, they move away from him. (Interview, social worker, rural county)



These children are isolated by the entire community.
(Interview, teacher, urban county)

Lack of adequate health services: The uncertainty of the autism condition and lack of adequate information from the medical personnel in hospitals increased chances of parents engaging in searches for any available treatment of autism. Parents of children with autism, regardless of religious beliefs, had visited a traditional healer.

I was confused, so I took him to a traditional healer because I was told it [the autism] was witchcraft. (Interview, Christian parent, rural county)

I went to many hospitals. At first I took him to a company hospital and they told me that they don't treat such illnesses. So I went to a 'mganga' [traditional healer]. (Interview, Christian parent, urban county)

I went to hospitals and when they told me that my child was not sick, I knew that it will be a problem. I went somewhere else. I went to see a traditional healer. (FGD, traditionalist parent, rural county)

Financial burden: Most of the study participants interviewed from both rural and urban counties expressed concerns that parents of children with autism on the Kenyan coast use almost all the money they have towards treatment of their child with autism. At all levels of the struggle for treatment, parents found themselves with no money, yet their child continued with the disorder.

The child did not improve after taking medication. We later left that one [the healer] but we had already lost all our money. (FGD, parent, rural county)

Some days back we were at Likoni at a traditional healer The father gave 30 thousands shillings and there were no changes. We were left with no money. (Interview, parent, urban county)

Also from the money point of view, depending on the setup of the family, if they don't have enough income to support this child parents tend to give up after using the little they have.
(Interview, clinical officer, urban county)

You may find that many of these children are found in poor homes so you get that parents look at it [the autism disorder]; they do not have money so they just leave it like that.
(Interview, social worker, rural county)

Care-giving burden: Most participants had the opinion that a child's lack of daily living skills was an impediment to parents of children with autism to engagement in income-generating activities. Parents were unable to leave their homes due to caring responsibilities towards their child with autism. These caring responsibilities led to lack of adequate time for paid work, home domestic chores and other activities.

He has not known even toileting skills, so I have to stay with him throughout the day. You can't even have time to go out to work or look for something to help you earn little money.
(Interview, parent, urban county)

Another problem is food. When eating you have to be there and help him eat because one of his hands is not able to hold anything. He has also not been able to think well, so you have to put the food for him and supervise him because when you give him food and you leave, he can even leave the chickens to eat with him. I don't have time even to sell vegetables in my kiosk. This has affected me financially.
(FGD, parent, rural county)

Adapted coping strategies

Participants in this study brought out two main coping strategies that parents of children with autism applied in their day-to-day caring of their child with autism. The first strategy was problem-focused and the second was emotion-focused.



Problem-focused strategies: The problem-focused strategies are directed at managing or altering the problem that brings the distress³⁴.

Diet Several interview participants from the urban county and a few from the rural county thought that avoidance of certain foods given to children with autism could control autistic behaviors. Some professionals seemed to advise parents on issues of diet.

He should not use sugar in his diet/food, should not take cow milk and other fruits like pawpaw, or anything with sugar. This makes him hyper. (Interview, parent, urban county)

We also advise the parents to be careful with issues of foods for example, because there are some types of foods which when taken by a person with autism worsens the condition. (Interview, teacher, rural county)

Certain foods are not recommended. I started taking the measures that my child avoids those foods. When I did that I saw many changes happening; like a lot of fear reduced; the hyperactive behavior has also reduced. I am grateful. (Interview, parent, urban county)

Respite care Respite care mentioned by parents was taking the child with autism to a boarding school. That was where the child would get better assistance.

For the case of my child, he is assisted in a boarding school. It has been helpful. (FGD, parent, urban county)

My assistance is continuing going to school. Boarding school is better. I can do other things at home when he is at school. (Interview, parent, rural county)

Emotion-focused strategies: Emotion-focused coping is directed at regulating the emotional response to the problem³⁴.

An important coping strategy mentioned by the majority of the participants was spiritual coping. This manifested itself in

belief and acceptance that the child's condition was part of a bigger plan, and in prayers and active searching for spiritual healing.

Belief in supernatural powers The belief that the child's condition was part of a predestined plan by God was raised by several parents. These parents then expressed an acceptance of this situation and it seemed to be a salient coping strategy in this region.

We have tried to treat him in the hospitals and have not got any success, so we see it as 'majaliwa' [God's wish]. (FGD, parent, rural county)

There are many things that were said but I did not want to listen to that because I know that on the way my child has been treated by various doctors with no success. I know that this condition is 'majaliwa' [God's wish]. (Interview, parent, urban county)

Spiritual healing Expectations of divine interventions were also highlighted by participants in this study. Spiritual or prophetic healing was highly expected during prayer sessions.

So I have not gone to a traditional healer because I believe in prayers, and that the prayers will heal my child. (FGD, parent, rural county)

I went for prayers and the man of God told me that this child has no problem, it is God who has blessed you with him just like that; we will pray for him and God will perform a miracle. (Interview, parent, urban county)

Because of her child's condition she decided to go to church for prayers. Prayers have helped her very much to accept and live with the child happily. (Interview, teacher, urban county)

If these things are given follow up and even the church people get involved, for example a brother to (...) was prayed for and got healed. Prayers work miracles. (FGD, teacher, rural county)



I went to a madrassa teacher [teaches Quran] and asked him to pray for my child. He asked me if at the mosque or at home. I said at home. (FGD, parent, urban county)

Prayers Prayers were perceived by parents as a powerful tool in enhancing their relationship with God. They believed that the child with autism was a test of their faith from God.

They say that it takes faith to be strong. It is our faith that is being tested. (FGD, parent, rural county)

Above all I thank God because I go for prayers, so I don't have to think about what other people say. (Interview, parent, urban county)

Discussion

The present study describes some of the challenges of living with a child who has autism in rural and urban settings on the Kenyan coast. Participants in this study included parents of children with autism and professionals who interact regularly with these parents and children with autism from rural and urban counties with diverse culture and religious affiliations. Religion and family values influence cultural perceptions of autism and the welfare of families. The study revealed that parents of children with autism living in this part of Kenya experience common challenges when caring for a child with autism. A number of key findings were observed. First, raising a child with autism on the Kenyan coast puts a tremendous strain on parents due to the stigma associated with the disorder. Second, the impact of societal negativity towards a child with autism may force parents to engage in a search for possible treatments. Third, the need for constant monitoring of the child with autism has negative economic impact on the parents. Fourth, parents apply strategies that are either problem-focused or emotion-focused to enable them to cope with the stresses of living with an autistic child.

The findings suggest that due to the stigma expressed by the community towards parents of children with autism in this region, shame was experienced by parents, and isolation of

the child and family was reported. Parents from both rural and urban counties, regardless of their religious affiliations or cultural beliefs, experienced social isolation of their child, community intolerance and problems negotiating public encounters. This insensitivity and negative comments made by community members resulted in parents perceiving themselves as social outcasts, negatively influencing their socio-emotional stability. Similar findings have been documented in India³⁵⁻³⁷. These findings also support the findings by Werner³⁸, who reported that parents spend most of their time dealing with the undesirable behaviors of the child. The results of this study suggest that stigma experienced by parents of children with autism is a global issue shared in both resource-rich and poor countries of the world. The results further suggest that autism seems to be underestimated in sub-Saharan Africa as parents from rich and poor settings seem to share equal consequences.

In this study, two major challenges are highlighted that are more common in resource-poor countries: financial burden and reduced time for economic activities. These factors increase the risks of poverty, leading to deprivation of basic family needs. Similar results have been noted by Montes and Halterman³⁹, in which there was an association between childhood autism and loss of family income. It was estimated that approximately 14% of family annual income went towards the care of a child with autism. The financial constraints for care of children with disability have been described in disability studies conducted in the region^{40,41}. Given that most of this region is resource-constrained, with a significant percentage of parents (up to 71%) living on less than US\$10 a day, the financial burden associated with having a child with autism is devastating for some families.

So how did parents of children with autism in this region deal with their challenges? The present study's results show that they used both problem- and emotion-focused approaches. One intervention that seems to be very popular among parents on the Kenyan coast is diet, where some foods or groups of foods are eliminated from the child's diet. Parents took these measures following advice by different



professionals they had consulted. The popularity of the diet intervention among parents of children with autism in Kenya could be explained by the fact that the Autism Society of America⁴² has endorsed the use of dietary interventions. Garvey⁴³ also highlighted the use of diet together with nutritional supplements in the treatment of autism. However, a recent review study has revealed that dietary therapy alone is not sufficient in the management of autism⁴⁴. There is need for more research on the use of diet in treatment of autism.

Respite care was viewed by participants to assist parents in the management of their child with autism. Taking a child with autism to a boarding school enabled the parent to have time for other household chores. This could suggest the disintegration of the extended family in the African context. Previously, parents in Africa depended on family members for respite care⁴⁵.

Spiritual coping, by belief or seeking prayer, is a salient approach for dealing with autism in this population. Some parents found solace in the belief that the presence of a child with autism in the family was planned by God. Parents utilized this strategy after their efforts and consultations to get treatment for their child were unsuccessful. In a way, parents are pacified by the belief that God wanted the child to have autism. Similar strategies have been described in other studies of families of children with autism^{15,46,47}.

Anticipation of a miracle through prayer dedications was mentioned by participants from both settings. There seems to be widespread speculations in both rural and urban settings that spiritual healing is possible through the upholding of strong faith in prayers. This phenomenon seems to play a specific role in the adaptation of parents of children with autism in this region. Not a lot of investigation has been conducted in this particular subject; however, a few studies have presented data to suggest that religious coping may help to reduce stress and depression in parents of children with autism^{46,48,49}. There is need for a study to explore the association between religious coping and parental adaptation.

Weaknesses of the study

This study was carried out in two of the seven counties on the Kenyan coast, thus these results may not conclusively describe the caring experiences of parents of children with autism from the entire coastal region. There is need for a study that would utilize study participants from the whole country, to provide a wider scope of views and perceptions that can be generalized to the wider Kenyan population. The socio-economic status of the participants could have been considered as a variable that could influence responses of participants, but data was not collected in this study.

Study implications and recommendations

The results demonstrate that having a child with autism puts an incredible strain on the personal and emotional resources of parents. This may be reduced by early identification that will lead to early intervention for children with autism in this area, as is described in studies from Western countries⁵⁰. Parents need to be empowered and supported within their counties and communities. A home-based participatory model has been used with parents of children with communication problems in the region to enhance communication skills between parents and children with communication disorders⁵¹. It is recommended that this model could be extended to parents of children with autism to strengthen parental resilience and to challenge stigma and discrimination⁵². It is also recommended that professionals engage parents in discussions related to parental beliefs about etiology of autism and available treatment options. These would help raise parental awareness and contribute towards them making optimal treatment choices.

Conclusions

This study observed a range of challenges encountered by parents from both rural and urban setups on the Kenyan coast that could have tremendous impact on the care of children with autism. Knowledge of parental experiences in caring for a child with autism is vital in addressing the unmet needs of



children with autism and their parents. This knowledge could be important in the design of community-based interventions where parents play a major role in the implementation and evaluation of the intervention.

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